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ABSTRACT

This practicum report describes development of a system of family support services for 56 parents of preschool handicapped children (ages birth to 3) in an early intervention setting. A preliminary survey was administered to determine family needs. A family support group was then developed which met monthly for fellowship, networking, work projects, and parent education. Individual family conferences were held to develop Individualized Family Service Plans (IFSP). Also, a parent handbook was developed and disseminated to parents. Results of a post-intervention survey indicated significant feelings of increased support and a positive shift in attitude by agency staff from a child-focused approach to a family-centered philosophy. Recommendations to others considering establishing such groups are offered and include: provide transportation and child care, develop a program committee made up primarily of parents to determine topics and activities, stress a family-centered philosophy in all staff development activities, and have an experienced parent partner help parents prepare for the IFSP meeting. Appendices include the parent survey, a parent letter, a parent support group information sheet, meeting/activity notices, and an IFSP model. (Contains 54 references.) (DB)

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Meeting the Needs of Parents of Preschool Handicapped Children Through Increased Support Services

by

Ernestine E. Cormany

Cluster 47

A Practicum I Report Presented to the
Ed.D. Program in Child and Youth Studies
in Partial Fulfillment of the Requirements
for the Degree of Doctor of Education

NOVA UNIVERSITY

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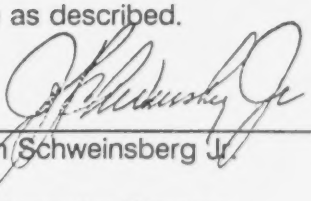
Verifier: 

John Schweinsberg Jr.

Executive Director

Title

Rockledge, Florida

Address

October 9, 1992

Date

This practicum report was submitted by Ernestine E. Cormany under the direction of the adviser listed below. It was submitted to the Ed. D. Program in Child and Youth Studies and approved in partial fulfillment of the requirements for the degree of Doctor of Education at Nova University.

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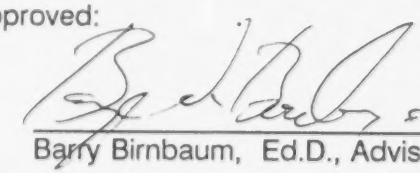

Barry Birnbaum, Ed.D., Adviser

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Problem solving projects call for the cooperation, participation, and support of many individuals. In recognition of this, the writer wishes to express her appreciation to the children, their immediate families, foster families, and extended families in The First Step Early Intervention Center, operated under the auspices of ARC-Brevard, Inc. Their time spent in completing surveys, reviewing documents, and assisting in the development of the parent handbook as well as their willingness to candidly share personal experiences and concerns added greatly to the successful completion of this project.

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ABSTRACT

Meeting the Needs of Parents of Preschool Handicapped Children Through Increased Support Services. Cormany, Ernestine E., 1992: Practicum Report, Nova University, Ed.D. Program in Child and Youth Studies. Preschool Handicapped Services/Developmentally Disabled Children/ Early Intervention/Parent Support/Self-Help Groups/Family Empowerment/Respite Care/

This practicum was designed to develop a system of family support services for parents of preschool handicapped children in an early intervention setting with consideration given to the multiple needs of families for formal and informal social interaction and an improved knowledge base regarding their child's disability and resources available. Services and materials were provided at no cost to families.

The writer administered a presurvey to determine family needs and a post survey to determine the increase of family perceived support; organized a family support group which met monthly for fellowship, networking, work projects, and parent education; scheduled individual family conferences to develop Individualized Family Service Plans; and designed a parent handbook for dissemination to all parents.

Analysis of the data revealed that attendance at the support group activities met the proposed expectations, that responses of the 56 parent participants on the post survey showed significant feelings of increased support and that agency staff showed a positive shift in attitude from a child focused approach to a family-centered philosophy.

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CHAPTER I

INTRODUCTION

Description of Community

The community setting for this practicum work is located in a county directly adjacent to a large metropolitan area in a rapidly growing southern state. According to 1990 census figures, the county showed a population of 405,494 residents. Projection estimates show heavy growth potential in the county of an additional 136,000 persons by the year 2000. Of the population, 91,314 are children and youth under the age of 18 and 16,988 of these children are between birth and age three. According to related statistics also compiled in 1990, 19.9 percent of the children live in poverty.

The county is comprised of several bedroom communities and beach/resort areas. The socioeconomic makeup represents a predominance of low to middle income families. Numerous inland pockets of the area are comprised of unskilled/unemployed black families with a rising concern for substance abuse and crime. The beach areas consist of a somewhat segregated population of white middle income families with a significant representation of upper income middle aged families and retirees.

The tourism industry and high technology corporate operations are employers for the majority of the work force. Geographically, the county is long and narrow and is conspicuously without a public transportation system.

Writer's Work Setting and Role

The work setting for the writer is an early intervention program for children from birth to age three with established conditions, developmental delays and multiple "high risk" factors. The children's program is operated under the auspices of a county wide not-for-profit organization serving clients with developmental disabilities (primarily mental retardation). The umbrella organization offers a continuum of services for all age groups with programs including a variety of components (i. e., information and referral, case management, advocacy, adult work training, residential placement etc.).

Although the organization has included services to children in their mission statement for the past thirty six years, very little emphasis has been placed on early intervention for infants and toddlers. Within the last year however, new interest has developed in serving children from birth to age three. This interest was prompted by P.L. 99-457, Part H, Education of the Handicapped Act Amendments. This new federal legislation mandates services for preschool children with special needs and their families.

With support and direction from the organization's Board of Directors and the acquisition of new funding, a variety of early intervention programs

have been added to the organization's menu of services for preschool children with disabilities. A new department for addressing services to children and youth has also been created.

In the summer of 1991, an agency public outreach and screening program was begun to assist with education, identification, and referral of eligible preschool handicapped children for early intervention services. Within the last year, the organization has grown from serving three children in one center based setting, to serving 34 children and their families via two satellite center locations and a home bound component providing services in individual homes and day care settings throughout the county. A full compliment of therapy services (physical, occupational, and speech) exists for assessment and treatment.

The writer's position with the organization is Director of Services for Children and Youth. This position was created one year ago through action of the Board of Directors. Relative to this practicum, the writer's role and responsibilities involve the identification of areas in the early intervention program which need improvement in order to provide comprehensive services to children and their families.

The organization's Board of Directors and the Chief Executive Officer (CEO) are available for direction and support as needed. A great deal of latitude for creative and innovative approaches to problem solving and program development is provided the writer. Open communication with the CEO has

been maintained. The writer regularly attends board meetings for the purpose of education and information.

The writer supervises a staff of nine professionals/paraprofessionals and seven volunteers. A team approach to problem solving and treatment is utilized. All staff members and volunteers are encouraged to offer input into program development and problem solving. All suggestions and opinions are respected. Regular input and sharing relative to this practicum work has produced support, enthusiasm, and a feeling of camaraderie.

CHAPTER II

STUDY OF THE PROBLEM

Problem Description

With the organization placing only minimal attention on early intervention services for preschool handicapped children in previous years, the programming which took place was limited in scope and included only child focused goals and objectives. Families were considered only in regard to meeting the young handicapped child's basic needs and were rarely consulted or included as a part of the treatment team.

Historically, the stress experienced by families who faced uncertainty about their child's future was rarely addressed. Contact with families had consisted primarily of informal brief inquiries of mothers during drop off/pick up times at the center. Fathers had been involved only by accident and no formal mechanism had been in place to encourage family involvement or networking.

With the advent of P. L. 99-457 and its mandate to include family needs as an integral part of service provision, new directions in program planning by all providers became necessary. Professionals and provider organizations who had previously failed to recognize that parents were better able to meet the

needs of their children when their own needs were getting met, began looking at programs in terms of "family centeredness". Use of an Individualized Family Service Plan (IFSP) as the preferred document to the Individual Education Plan (IEP) was considered.

Although P. L. 99 - 457 was passed in 1986, the writer's organization and the state as a whole had been slow in planning for full implementation. Even with "family driven" initiatives as only a part of this legislation (perhaps the easiest part of the mandate to plan for), the state had cited budget constraints and service fragmentation as primary barriers to implementation. The writer's organization had not responded due to minimal attention to children's services in previous years and a lack of adequate planning and leadership in this regard.

Briefly stated, the problem which existed within the writer's organization was that parents of preschool handicapped children in the early intervention program were not receiving the support necessary to meet their needs.

Problem Documentation

Evidence of this problem was supported through observation, reviews of the records, informal parent surveys, and interviews. In a case by case review of the children's Habilitation Plans which were collectively compiled by Health and Rehabilitative Services (HRS) and the writer's organization, the only hint of parent involvement was a signature indicating agreement with the plan or

documentation that the family had been notified of the Habilitation Plan meeting and had failed to show. All plans included "child focused" goals and objectives only which were initiated primarily by the professionals involved in the child's treatment.

In interviews with parents and teachers, the writer discovered that specific conference times for information exchange, input, training, and support of parents had never been scheduled. Parents and teachers appeared anxious and reflected feelings expressing a need for better communication.

In contacts with offieers of the two Parent to Parent organizations in the county, records showed that none of their regular members had children in the birth to age three range. Periodic inquiries had been received from these groups regarding accessing services for young children but group involvement had not occurred. In contacts with two internal parent groups affiliated with the writer's organization, membership records showed only parents of children over the age of 21 had been involved. Minimal attempts by these groups to incorporate parents of young children had not resulted in the attendance of a single parent of a young handicapped child in recent years.

During an informal coffee hour planned for parents of preschoolers in November, 1991, parents were informally surveyed regarding their needs and desires for future contact and services. Nine of the eleven parents attending expressed a need for their own organized parent support group meeting and listed "informal networking" as their greatest need. Eight of the eleven mothers

attending expressed a need for their spouses to attend also and meet other families. Talking with the parents informally resulted in frequent comments regarding feelings of isolation and aloneness.

Causative Analysis

In a general overview on the cause of the problem, it became apparent that the lack of attention to the needs of parents of young handicapped children was not confined to the writer's work environment. It appeared that this problem had been universally recognized as a major concern, therefore lending itself to be addressed by the recent federal legislation for corrective action from a broader perspective.

Perhaps yesteryear's social stigma attached to individuals who were "different" and to those parenting these children kept advances from being made earlier. Only within the last few decades has it been socially acceptable to announce that a family member has "special needs" and to advocate for services for all those impacted. At one time, professionals almost automatically recommended institutionalization of developmentally disabled children, giving little attention or credit to parents who preferred caring for their children at home.

The system often failed to recognize that with appropriate support, families were capable of caring for their own children. Well meaning professionals, often caught up in "enabling" families, neglected to look at the

strengths in family systems. Assertiveness training, advocacy, and "empowerment" were not considered as ways of supporting families .

These concerns were echoed in the writer's organization and were considered when pinpointing the specific causes in the work setting. It was evident that agency guidelines for writing Habilitation Plans had been handed down from an era of "child focused" programming which excluded the family. Agency teachers and therapists had failed to see the importance of working with families and had difficulty with "role release" and recognizing parents as the child's first teachers.

Another cause for lack of family support in the writer's organization centered around staff concerns. Sufficient time, resources, and training had not been afforded the Early Intervention Coordinator and other staff members for planning parent functions. Dealing with parent issues (i. e., denial, guilt, and marital discord etc.) required advance preparation and special skills in order to be addressed appropriately in support group meetings or individual conferences. Concern due to confidentiality issues had prohibited staff members from sharing information (i. e. names, addresses, and phone numbers) between families with similar problems in order to encourage informal networking opportunities.

The timing and meeting format had also presented possible obstacles to parent involvement/support. With the majority of the organization's activities occurring during "daytime" hours, this had prohibited the involvement of most

fathers and working mothers and had given them limited access to staff for addressing questions and concerns. Some parents did not enjoy a meeting format focusing on their perceived "problems" and needed more subtle ways of getting their needs met.

Other than agency brochures and application packets, families had not been given written information to assist them in their understanding of the purpose and value of early intervention programs. Program specific information was also nonexistent.

Relationship of the Problem to the Literature

A review of the literature showed evidence and documented the fact that parents of preschool handicapped children had a multitude of concerns which lead to increased needs for support. Although these families could not be considered a purely homogeneous group, the existing literature reflected recurring themes, concerns, and emerging patterns in the difficult adjustment process.

Deiner and Whitehead (1988) and Turnbull and Turnbull (1985) discussed the overwhelming emotions and disappointments experienced by families. Disillusionment, vulnerability, and aloneness were seen as some of the more devastating feelings. These findings were corroborated by Koch and Dobson (1971) and Perske (1981) who addressed the emotions expressed in

the very early years of parenting a "special needs" child. The feelings of guilt, ambivalence, and even repulsion were explored.

When a child was perceived as atypical, the parent related stress increased dramatically (Heterington, 1984; Mash, 1984). Some families were able to successfully cope while others experienced devastating results on the family unit. The types of stress reported appeared to have some correlation to the nature of the child's problem and age. Evidence of the number of single parents shouldering the responsibility for their handicapped youngsters in the writer's work setting as well as other related data in the literature reviewed substantiated the alarming rate of marital breakup and discord among these families (Brown & Pacini, 1989; Koch & Dobson, 1971; Mash, 1984; Williams, 1987).

Paramount for families of severely disabled children were the financial struggles presented. Research indicated that many families were burdened with mounting medical bills with no end in sight (Grieffel, 1991; Kobliner, 1991; Koch & Dobson, 1971). Davis (1990) agreed and discussed the further complications which often necessitated mothers quitting their jobs to care for the disabled child. He also elaborated on the poor work performance of parents who were struggling with the difficult demands of parenthood. The high numbers of families who qualified for Medically Needy assistance and Medicaid payments reflected the validity of this research as it applied to the writer's work setting.

According to Summers, Bridge, and Summers (1991) it was estimated that ten percent of all school-age children in the United States required special education and approximately 80 percent of these children had siblings. Juggling the demands of handicapped and nonhandicapped children in the same household also presented further evidence of the demands placed on families for which they needed additional support (Powell & Ogle, 1985; Waggoner & Wilgosh, 1990).

According to Blacher (1984) families of handicapped children pass through a series of stages in their adjustment to parenting a child with special needs. Because families often became "disabled" as well as the child, Fotheringhan & Creal (1974) pointed out that during the process of incorporating a handicapped child into the family makeup--a new family unit emerged. This family unit then often passed through a series of stages collectively as well as individually. Large numbers of studies explored these stages of adjustment. Each stage had special needs for support (Blacher, 1984; Friesen, Griesbach, Jacobs, Katz-Leavy, & Olson, 1988; Lazzari & Kilgo, 1989; Powell & Ogle, 1985).

Mackeith (1973) stated in his research that families of handicapped children faced a number of critical transition periods which produced stress and often produced their own stages of adjustment. Four periods were discussed: 1) the initial realization; 2) the beginning school process; 3) the school exit; and 4) the parent's aging years.

With research reflecting the multiple needs of families, the literature reviewed showed evidence of a need for appropriate assessment instruments to assist in determining family needs (Bailey & Simeonsson, 1988; Chandler & Lubeck, 1985; Leviton, Mueller, & Kaufman, 1992; Sexton & Thompson, 1990; Simeonsson, Bailey, Huntington, & Brandon, 1991). Herman & Hazel (1991) reported on the results of their study regarding assessment instruments. They showed the need for four core services: (a) case management, (b) parent training, (c) respite, and (d) short term out of home placements during crisis. On the other hand, Bailey and Simeonsson (1988) reported that two of the biggest needs found in their assessment of families was for informal networking and more "time for self". It appeared that the informal assessment completed in the writer's work setting would corroborate the Bailey and Simeonsson work.

As mentioned earlier, one of the primary causes for limited attention to the specific needs of families had been the "child focused" philosophy of the past. Developments in recent years have seen providers of services as moving steadily away from gearing services only to the child with the disability (Dunst, Johanson, Trivette, & Hamby, 1991). In keeping with this, numerous researchers have explored the need for adequately trained professionals to work with parents (Bailey, Palsha, & Simeonsson, 1991; Kinney, Dittmar, & Firth, 1990) and the issue of recognizing parents as experts about their own children (Brower & Wright, 1986; Roberts, McLaughlin, & Mulvey, 1991). Sloman and Konstantareas (1990) indicated that professionals had also often been hesitant

to provide adequate and complete information and diagnosis to families, thus, adding to their confusion, denial, and antagonism. This frustration was often expressed during intake interviews with families and in subsequent informal conversations with families in the writer's work setting. The primary target of this concern appeared to be the various medical professionals with whom they interacted in their attempt to get answers.

As has also been explored in some depth previously, a large amount of literature exists which documented the lack of inclusion of family needs in the standard IEP. Passage of P.L. 99-457 has now provided the impetus for professional service providers to include family strengths and needs in planning for services (Deardorff, 1992; Leviton, Mueller, & Kaufman, 1992; Sexton, Burrell, & Thompson, 1990; Zeitlin & Williamson, 1988).

Of primary concern to the writer has been the nonrecognition of the special needs of fathers. Although some increase has been seen in the attention given to fathers in recent years, a lack of inclusion continues to exist in specifically addressing their unique concerns. In a study by Sparling, Berger, and Biller (1992) many primary caregivers are fathers, yet only two percent of the IFSP goals relate to them specifically. In research by Sandler, Coren, and Thurman (1983) it was noted that when mothers were given support and their attitudes became more positive, fathers felt ignored and had adverse reactions. LaBarrera and Masterson (1988) and Davis (1990) also pointed to the need for

strengthening the marital relationship by addressing the needs of fathers through helping them with specific coping mechanisms.

Up to this point, only the needs of families who cared for their disabled children in their own homes has been explored. The literature however also addressed the additional confusion and stress placed on families by physicians and well meaning family members and friends who encouraged institutionalization of handicapped children (Blacher, 1984; Perske, 1981). Springer and Kantrowitz (1990) discussed the feelings experienced by parents who also contemplated adoptive placement of their handicapped offspring. The issue of foster placement as another alternative was discussed by Heighway, Webster, and Snodgrass (1988). Although the writer's practicum primarily concerned families whose children were maintained at home, these concerns and dilemmas were recognized.

CHAPTER III

ANTICIPATED OUTCOMES AND EVALUATION INSTRUMENTS

Goals and Expectations

The overall goal of the practicum experience was that parents of children participating in the preschool handicapped early intervention program would have opportunities to express their needs and participate in meaningful experiences to benefit themselves and their children. The expectation was that families would express feelings of increased support.

Expected Outcomes

The following goals and outcomes were projected for this practicum. The first expected outcome will be that all Habilitation Plans which currently reflect only "child focused" goals and objectives will be replaced by Individualized Family Service Plans (IFSP) which reflect the needs of both children and families. The standard of achievement will be that 100 percent of the client records will include the IFSP by the conclusion of the three month practicum period. This will be evaluated by a review of the client records.

Second, families will receive additional information regarding early intervention benefits and specific program related materials. The standard of achievement will be that 100 percent of all families will receive a new parent handbook. This will be evaluated by a review of the new handbook for inclusion of appropriate information and a review of records indicating handbook distribution.

Third, at a minimum, one support group meeting or activity will be planned monthly and all parents invited to attend. The standard of achievement will be that this will be achieved 100 percent of the time with written documentation that all center based and home based parents have been invited and that 40 percent of the parents (based on one parent per child) will attend two out of the three meetings. This will also be measured by feelings of increased support during the administration of a parent survey at the conclusion of the three month practicum experience. This will be evaluated and supported by a report prepared by the Early Intervention Coordinator to the program director.

Fourth, 30 minutes of "networking" time will be built into each family support group meeting or activity. The standard of achievement will be that this will occur 100 percent of the time and that families will show increased feelings of support indicated by results of the parent survey at practicum conclusion. This will be evaluated through personal observation.

Fifth, a family support activity will be scheduled during the evening hour or during a weekend in order to include fathers and working mothers. This will occur a minimum of one time during the quarter. The standard of achievement will be that 100 percent of the families including fathers and working mothers will be invited to participate. At least 20 percent of the fathers and working mothers will attend. This will evaluated through report of the Early Intervention Coordinator and by a review of the records.

Measurement of Outcomes

A written parent survey (see Appendix A) was designed by the writer after a review of the literature and an examination of the pertinent hard data. This survey included twenty statements which reflected the needs of families who were parenting handicapped children. Parents indicated the extent of their needs and concerns by responding to statements on a scale ranging from 1 to 5. The items were ranked from definitely not a concern/interest (1) to definitely a concern/interest (5). The survey concluded with a request for parents to choose three items about which they had the greatest concern.

This tool was administered during the first week of the practicum period as a presurvey and again during the two week period following the three month practicum experience as a post survey. Items on the survey which showed significant need and could be addressed within the scope of the practicum were those items primarily used to measure the success of implementation.

Administration took place during face to face contacts with families or by mail when necessary with an accompanying letter which explained the purpose and intent of the survey (see Appendix B).

Support group attendance records were kept by the Early Intervention Coordinator relative to the types of support activities and numbers of nonworking mothers, fathers/working mothers attending each session. Antidotal records were kept by the writer regarding staff and family interest, participation, and reactions to the IFSP training and implementation. A daily log was also kept by the writer to record events and highlights of the practicum for use in subsequent journal articles and disseminations.

CHAPTER IV

SOLUTION STRATEGY

Discussion and Evaluation of Possible Solutions

The problem addressed in the writer's work setting was that parents of preschool handicapped children in the early intervention program were not receiving the support necessary to meet their needs. Prior to the implementation of this practicum a review of the literature was completed to ascertain possible solutions which had been tried before by others who faced similar problems.

The most popular solution presented in the literature appeared to be the use of the "support group" technique. This approach had been universally successful in bringing people together who shared similar experiences and concerns. It was estimated that 500,000 support groups of different types exist in the United States serving nearly 15 million people (Hecht, 1986).

In regard to families parenting children with special needs, Herman and Hazel (1991) and Heterington (1984) reported that parents who were single, divorced, or widowed profited through support groups even more than married couples. These support groups appeared to serve the purpose of providing an

extended family. Lillie (1972) also addressed the need to include grandparents in these groups.

Using support groups to enhance parenting skills was measured in a study by Pond and Gilbert (1987) who pointed out the importance of having a strong and capable group leader. Family support groups provided a "base" and gathering place for families who felt isolated according to Horel (1987) and seemed to do best where flexibility was present. Roberts, McLaughlin, and Mulvey (1991) discouraged groups from becoming locked into a mindset regarding outcomes.

According to the literature, public schools often fail to recognize that a need exists for these parent groups. A successful project which took place in an American Indian community school district showed an improvement in children when parents got their own needs met (Berlin, 1990). Carter and Bassett (1985) corroborated this finding in a similar study in Georgia.

With the passage of P. L. 99-457 and the emphasis on working with families, one of the major initiatives for providing services to parents has been through informal networking opportunities. Bailey, Buyssee, Edmondson, and Smith (1992) completed a study on this service delivery model. The study was somewhat limited however, due to unknown factors on how representative the sample was and also the generalizability. There is growing recognition that specifically helping families acquire new friends and teaching them new skills to develop friendships has positive outcomes (Tracy, 1990).

Hulnick and Hulnick (1989) indicated that professional counseling services provided a valuable means of support to families of handicapped children. They emphasized the importance of coming to grips with feelings of guilt, self-punishment, and self-abuse. Because children with disabilities often fall victims to abuse, DeLollis (1985) and Roberts, McLaughlin, and Mulvey (1991) found positive outcomes through counseling with families whose children were considered at high risk for abuse.

In another study on the effects of counseling as a support mechanism, Toseland, Rossiter, and Peak (1990) compared the effectiveness of individual and group counseling. Participants in both intervention settings experienced significant improvements. The results of their study showed evidence that psychological issues responded best to individual counseling and social support issues responded best to group intervention.

Another form of counseling which was presented in the literature was an interim crisis management technique. Samuels and Balter (1987) reported on their use of telephone "Parent Warmlines". This project utilized a 24 hour a day telephone service staffed by volunteer doctoral students. Great success was seen in helping families who needed a "listening ear" and periodic referrals for additional services.

Further review of the literature showed respite care as one of the most needed and least available support services for families according to Deiner and Whitehead (1988). Respite care which gives a break to the primary

caregiver of a handicapped child is often the only relief a family has from the physical and emotional demands of the burden of chronic care. Halpren (1985) found that the longer the respite period, the greater the family's improvement in functioning. Similar findings by Botuck and Winsberg (1991) showed change in maternal mood, well-being, and activity patterns before, during, and after respite.

The literature also revealed special projects and ways of supporting fathers/male caregivers. Davis (1990) suggested videotaping technical or specialized training sessions which took place in center based programs to be shown to fathers at home. Giving fathers special assignments which suited their personalities (i. e., talking with legislators to advocate for children's services) made them feel they were contributing. Using fathers in conjunction with special education leaders to lead parent meetings was also recommended (Sparling, Berger, & Biller, 1992).

In addition to these ideas generated during the literature search, the writer considered the following other solutions as well: (a) developing a family to family support program within the organization utilizing the linkage of parents who have adult handicapped children with parents of infants and toddlers, (b) planning a home visit once each month with families whose children attended the center based program, (c) establishing a newsletter for families regarding program happenings and including developmental milestone information, (d) making an effort to provide appropriate male volunteer role models to assist

single mothers with parenting concerns, and (e) the establishment of a parent exercise class to provide relief from stress and encourage networking.

As a critique of the solutions presented, the writer believed that the solutions involving the establishment of support groups, informal networking systems, a parent handbook, and the implementation of the IFSP had the greatest merit for use. The hard data presented from the work setting also showed strong evidence that families had expressed a definite interest in these areas and would likely buy into them. Although the other possible solutions had significant merit, the lack of staff and available resources along with the time constraints within the three month practicum period prohibited their implementation. Elements of many of these possible solutions however were incorporated to some extent within the scope of the other solutions selected.

Description of Selected Solutions

The family "support group" meeting technique and its accompanying informal networking component were targeted as primary solution strategies for implementation. It was decided that one support group activity would take place each month with special attention being given to meeting times which could accommodate the schedules of fathers and working mothers as well as nonworking mothers. Meeting themes were designed to be as nonthreatening and supportive as possible in order to insure interest and involvement.

The use of the IFSP conference time was selected to provide one-on-one support to parents. Each family in the program was targeted to have a private conference scheduled to review and update their "plan" for provision of services to include family strengths and needs as well as child focused goals and objectives.

In order to address the expressed need for additional information, a parent handbook was planned. Information on various disabilities, developmental milestones, the effectiveness of early intervention programming, the organization's program in particular, and available community resources were among the items to be included.

Report of Action Taken

In order to set the stage for the practicum, the writer reviewed implementation plans with the organization's Board of Directors, the Executive Director, the Early Intervention Coordinator, and the center and home-based teachers and therapists. Enthusiasm and ownership were developed in this team approach to providing increased family support.

A small budget of $250 was set up for materials, supplies, refreshments, and printing. Copies of the state approved IFSP were obtained and samples of parent handbooks from similar programs were reviewed.

The presurvey was administered during the first week of the practicum during drop off and pick up times at the center, home visits, and personal

conferences. Since some children were absent from the program during this time, surveys were mailed to families who had been missed.

Results of the surveys were used to determine needs and plan the format, activities and topics for the support group meetings. One meeting/activity was planned for each of the three months of practicum implementation with thirty minutes built into the schedule to allow for informal networking and conversation. A Parent Support Group Information Sheet was prepared to explain the purpose, activities, membership etc. of the group (see Appendix C). Notices were distributed approximately ten days in advance of each meeting/activity (see Appendix D) and follow up phone contacts were made to families on meeting days to encourage attendance. A Release of Information Form (see Appendix E) was designed to allow the organization to share basic information to encourage informal networking.

The introductory month was planned with an "Italian Night Out" theme. The evening hour was used to allow flexibility for all family members with food as a prime motivator for participation. Get acquainted activities and input from families on suggested future activities were the focal points of conversation. Child care was provided for the children with special needs and their siblings.

The second month's activity consisted of a morning coffee meeting immediately following the drop off time of children for the center based classroom program. An agency van was used to transport children and families who were served via the home based model. Child care was again

provided. The future direction of the group and the IFSP were the primary topics addressed at the meeting. Sufficient time was also planned at the conclusion of the formal meeting time to allow for refreshments and informal conversation.

Month three consisted of a Saturday afternoon work project concluding with a family cookout. This took place at the conclusion of the first week of the fall term. One of the fathers had designed a child's wooden art easel which could be assembled within the allotted time. Construction supplies were purchased for making easels for each of the classrooms. Fathers worked together cutting, sanding, assembling, and painting the easels along side male spouses of staff members who also participated. Mothers spent time visiting informally and preparing for the cookout. Following the meal time, an overview of the new school year was given and slides were shown of activities which had taken place in the classroom during the first week of school.

Throughout the practicum period work progressed on updating each child's "plan" to include an IFSP which was family-centered. The first two weeks were spent with inservice training for all staff on the importance of a family-centered philosophy and the use of the new IFSP document. The staff and a select group of parents were fortunate enough also to enroll in a two day workshop which was being presented locally by trainers from the state early intervention program office.

Following the training, a schedule was established for meeting with each family and those team members designated by the family to participate in the development of their IFSP. It was after the first two meetings that the writer discovered a slight resistance from a family on "why" the center was interested in changing the child focused plans to include "family" goals and objectives. It was clear that more training and information needed to be given to families on how this could "help" them and that it was not to be intrusive in nature. Plans were then made for incorporating this rationale and training into the next support group meeting. A pre-meeting period before each IFSP team meeting to address family concerns was also initiated. This slight alteration in implementation proved to be a workable solution.

During the first family support group meeting the need for a parent handbook was discussed. A volunteer was solicited to serve as the parent representative to assist in its development. Subsequent to this, a meeting was held between the organization's staff and the parent representative to outline the format and review material to be included. The parent representative came prepared with a list of questions and information which she had developed after talking with other families in the program.

Eight weeks were spent in developing the material for the handbook and in its review. Only a slight delay was experienced in getting the approval of the Board of Directors on the revision of the admission policy on AIDS related cases for handbook inclusion . The writer was also fortunate to get the support

of a community service organization in designing and purchasing a hard cover for each of the handbooks. Dissemination took place during the last week of the practicum.

CHAPTER V

RESULTS, DISCUSSION, AND RECOMMENDATIONS

Results

Parents of preschool handicapped children face a multitude of concerns with needs which call for specialized support systems. Evidence existed that these needs were not being adequately met in the writer's early intervention work setting. The solution strategies utilized during this practicum included the organization of a parent support group and an informal networking system to provide meaningful friendships and social/emotional support. Also, in order for families to express their needs and help in the development of a plan for services, the Individualized Family Service Plan (IFSP) was initiated to provide a family-centered approach. A parent handbook was also designed to provide comprehensive information for families.

The outcomes and results relative to each are presented as follows. The first outcome was that all Habilitation Plans which reflected only "child focused" goals and objectives would be replaced by the IFSP (see Appendix F). A review of the client records at the completion of the three month practicum indicated that 34 out of 34 or 100 percent of the families had an IFSP. This was

accomplished through the systematic scheduling by teachers and the early intervention coordinator. Families were consulted concerning the date/time of the IFSP team meeting and were allowed to invite those family members and professionals whom they desired to attend.

Second, the outcome projected was that families would receive additional information on early intervention benefits and specific program related materials in the form of a parent handbook. A review of the records indicated that 34 out of 34 or 100 percent of the families received this handbook. Parent input in the design was guaranteed through a parent representative on the committee which developed all material included.

Third, the outcome to be achieved was that one support group meeting or activity would be planned monthly with 100 percent of the parents invited to attend. It was projected that 40 percent of the parents (based on one parent per child) would attend two out of the three meetings. A review of the records showed that 100 percent of the parents were invited to the three meetings/activities. Table 1 outlines the attendance during these events. Although the three activities showed very little variance in attendance, results indicated that an attendance of 33, 30, and 3l out of 56 parents or over 50 percent at each meeting/activity was achieved. Attendance by at least one parent at two out of three functions was also achieved by 29 parents out of 56 or 51.7 percent. It was not surprising to learn that the best attendance by fathers/working mothers was at the weekend work project.

Table 1

Parent Participation in Support Group Activities

Activity	Attendance					
	Nonworking Mothers		Fathers and Working Mothers		Combined Participation in 2 of 3 Activities	
	Number	%	Number	%	Number	%
Italian "Night Out"	24	42.9	9	16.1	33	58.9
Morning Coffee/Meeting	27	48.2	3	0.5	30	53.5
Weekend Work Project/ Cookout	19	33.9	12	21.4	31	55.3

Note. N= 56 parents representing 34 family units.

Results indicating feelings of increased support are shown in a comparison of the presurvey findings and the post survey findings in Table 2. By totaling measurement Scores 3 (occasionally a concern/interest) through 5 (definitely a concern/interest) in the presurvey and again in the post survey a considerable difference was seen in certain key items. Items Number 1 (Need more information about child's disability), Number 2 (Need to meet others with similar concerns), number 4 (Need help with activities to do at home), number 10 (Need more time with staff) and number 17 (Need social life with other parents) were directly addressed during the practicum and showed significant improvement.

Table 2

Rated Importance of Parent Needs/Concerns

Item	Pretest / Post test	Extent of Concern 1 Low	2	3	4	5 High
* 1. Need more information about child's disability.		6	11	10	6	23
		10	19	9	5	13
* 2. Need to meet others with similar concerns.		3	5	16	8	24
		14	16	15	2	9
3. Concern about classroom/home visit.		20	17	9	4	6
		21	19	8	3	5
* 4. Need help with activities to do at home.		10	9	12	7	18
		17	14	9	5	11
* 5. Partner in denial.		11	9	18	9	9
		16	8	17	7	8
6. Concerns about discipline.		8	7	22	12	7
		5	14	19	12	6
7. Need time for self.		2	11	9	26	8
		5	12	8	21	10
8. Need/desire respite.		5	4	7	12	28
		6	6	7	14	23

Table 2

Rated Importance of Parent Needs/Concerns

Item	Pretest / Post test	Extent of Concern 1 Low	2	3	4	5 High
* 10. Need more time with staff.		8	5	19	17	7
		17	16	10	9	4
* 11. Need listener when feeling blue.		19	10	11	9	7
		20	14	7	9	6
12. Need day care.		31	11	9	4	1
		26	7	12	6	5
13. Need transportation.		4	11	19	8	14
		6	10	17	9	14
* 14. Need developmental milestone information.		18	13	10	10	5
		14	21	10	8	3
15. Need financial help with child's needs.		25	9	9	4	9
		24	7	11	6	8
16. Need help with food/shelter.		21	8	8	7	12
		13	15	10	6	12
* 17. Need social life with other parents.		12	3	17	11	13
		21	16	8	4	7
18. Need exercise class to relieve stress.		22	4	15	2	13
		21	4	12	3	16

Table 2

Rated Importance of Parent Needs/Concerns

Item	Pretest / Post test	Extent of Concern 1 Low	2	3	4	5 High
* 19. Need information about community service.		4	3	11	7	31
		11	15	9	5	16
20. Need more time with other children.		5	17	15	9	10
		8	10	17	9	12

Note. * Indicates items which were addressed in the scope of the practicum. N=56.

Fourth, the outcome presented was that 30 minutes of "networking" time would be included in each family support group meeting/activity. This was achieved by personal observation 100 percent of the time. As indicated in Table 2 this was perhaps the major factor responsible for the significant improvement seen in the post survey results of items 2 and 17.

Finally, the fifth outcome projected was that a minimum of one family support activity would be scheduled during the evening hour or during a weekend in order to include fathers and working mothers. The standard of achievement was that 34 out of 34 or 100 percent of the families would be invited and at least 11 out of the 56 or 20 percent of the fathers and working mothers would attend one function. Due to the interest in making these meetings/activities as convenient as possible, two of the three activities were

scheduled within these designated time frames. One hundred percent of the parents were invited and results showed that 9 out of the 56 or 16.1 percent of the fathers/working mothers attended the Italian Night Out and 12 out of the 56 or and 21.4 percent attended the work activity/cookout.

Discussion

A large body of research exists documenting the overwhelming concerns and unmet needs of parents of preschool handicapped children and their extended families. The presurvey used as a needs assessment and the resultant positive data seen in the post survey gave credence to the fact that families were hungry for support and would respond positively when opportunities were presented.

The aloneness felt by families which was expressed by Bailey and Simeonsson (1988) and Perske (1981) was corroborated in this problem solving experience during personal contacts with families. The zest with which they responded to the networking opportunities and their eagerness to sign the Release of Information Form in order to be included in interactive activities showed their need for relationships with others experiencing similar problems.

The success of the practicum experience was well documented by comparing the presurvey results in Table 2 on Items 2 and 17 in particular which showed that the needs expressed by families for social support were nearly cut in half during the post survey administration. This fact alone

indicates that a continuation of the support group meeting/activity format and the informal social networking counterpart are warranted as permanent components of the early intervention program.

Further reviews of the surveys revealed a need for financial assistance for such basic items as food and shelter as well as financial assistance in meeting child related needs and transportation concerns. This was congruent with the literature reviewed (Davis, 1990; Grieffel, 1991; Kobliner, 1991; Koch & Dobson, 1971). It was not surprising that Items 13, 15, and 16 relative to these concerns remained virtually unchanged from the presurvey to the post survey period since this was not addressed directly within the scope of the practicum. By nature, these needs require significant case management activities and linkage in order to show improvement. Consequently, they were built into the IFSP's for families expressing such needs.

Also it was interesting to note that responses to Items 7 and 12 regarding needs for day care and "time for self" appeared to show an increase during the post survey administration. This lead the writer to believe that families may have felt more comfortable and open in expressing their feelings after forming positive relationships with the staff and other parents.

Excellent attendance at the planned functions during the practicum was a welcome occurrence. This was due in part to the hard work of the staff and a few key parents who had been instrumental in advocating for the support group formation initially. The attendance by fathers and working mothers at the

weekend work project was inspiring and perhaps a result of the nonthreatening format of the activity and the duration of the groups existence.

A further implication of the project's success was the family involvement seen in external activities. It was interesting to observe that when two of the parent support group members were encouraged to take part in community advocacy activities, they were eager to do so. They became active in a countywide referendum to provide additional funding for children with special needs. They marched, attended meetings, and spoke to congressmen about their needs. One parent also joined the speaking circuit with the writer to create public awareness of early intervention programs. Davis (1990) had suggested involving fathers in these types of activities. Attempts at encouraging fathers however, in the writer's work setting were met with reluctance.

The research of Bailey, Palsha, and Simeonsson (1991) and Kinney, Dittmar, and Firth (1990) which addressed the need for adequately trained professionals in a family-centered approach was of special interest to the writer during this practicum period. The attitude changes which took place in the children's program staff following the inservice training on the IFSP were particularly noteworthy. For instance, one very important aspect of this staff development process was the interest in beginning arena assessments with families present. The writer had previously been unable to get cooperation in this regard from the therapists and teachers. Suddenly, following the IFSP

training they became enthusiastic about the concept and this assessment method was implemented the week following practicum completion. The writer's only regret was that a staff attitude survey on family centered philosophy had not been administered prior to practicum implementation to record this remarkable staff growth.

An unanticipated result of this practicum experience has been the respect which this parent group received from the other departments in the writer's organization. The adult division and the residential division have begun looking at revitalizing their parent groups to incorporate some of the activities and enthusiasm of the children's support group. The Board of Directors also suggested that a liaison be elected from the children's parent group to serve as a non-voting member of the board to assist in information exchange and program development. The parent group has welcomed this opportunity and has elected their liaison as well as their own officers to serve for the coming year.

In summary, this project has provided increased support for families of young children with special needs. It has been proactive and provides the impetus for future program development and a sound base on which to grow. It has been advocacy oriented, exciting, and heartwarming.

Recommendations

Based on experience gained during this practicum, the following recommendations are offered:

1. That confidentiality and sensitivity be maintained in all situations with special attention to nonthreatening meetings/activities.

2. That meetings/activities be planned to address the needs and concerns of all socioeconomic and cultural groups.

3. That transportation and child care be provided.

4. That an interest inventory be completed by the case manager regarding hobbies and leisure activities to assist in networking opportunities.,

5. That a program committee made up primarily of parents be formed to poll the interests of support group members regarding topics/social activities for each function.

6. That a line item be added to the organization's annual budget to allow for a continuation of the support group activities, provide materials, and allow for parents to take advantage of training and conference opportunities.

7. That attention be given to maintaining a family-centered philosophy in all staff development inservice activities.

8. That families be well grounded in their understanding of the IFSP and that a experienced parent partner be assigned to work directly with the family in preparing for the IFSP meeting.

9. That the writer's work setting expand their family support program in the future to address the overwhelming need expressed for respite care.

Dissemination

Interest in this project by other community and state groups has been fostered by the need for developing family support systems in conjunction with the final year of state planning dollars available from the federal government under P.L. 99-457. The Florida First Start program has visited the writer's work setting to observe this model and another highly respected early intervention program in the county has requested information for replication.

Plans are also being made by the writer to disseminate materials to the Florida Interagency Council for Infants and Toddlers (FICCIT) and the state Parent Resource Organization (PRO). The writer has also contacted the professional journal, Infants and Young Children, regarding their interest in manuscripts dealing with parent support. An affirmative response has been received and plans are being made to submit an article for their consideration.

References

Bailey, D. B., Buyssee, V., Edmondson, R., & Smith, T. M. (1992). Creating family centered services in early intervention: Perception of professionals in four states. Exceptional Children, 58, 298-308.

Bailey, D. B., Palsha, S. A., & Simeonsson, R. J. (1991). Professional skills, concerns, and perceived importance of work with families in early intervention. Exceptional Children, 58, 156-163.

Bailey, D. B., & Simeonsson, R. J. (1988). Assessing needs of families with handicapped infants. Journal of Special Education, 22, 117-127.

Berlin, I. N. (1990). The role of the community mental health center in prevention of infant, child, and adolescent disorders: Retrospect and prospect. Community Mental Health Journal, 26, 89-105.

Blacher, J. (1984). Sequential stages of parental adjustment to the birth of a child with handicaps: Fact or artifact? Mental Retardation, 22, 55-68.

Botuck, S., & Winsberg, B. G. (1991). Effects of respite on mothers of school age and adult children with severe disabilities. Mental Retardation, 29, 43-47.

Brower, D., & Wright, V. (1986). The rubberband syndrome: Family life with a child with a disability. DesMoines, IA: Iowa State Department of Education, Mountain Plains Regional Resource Center, & Nebraska State Department of Education. (ERIC Document Reproduction Service No. ED 250 255

Brown, R. T., & Pacini, J. N. (1989). Perceived family functioning, marital status, and depression in parents of boys with attention deficit disorder. Journal of Learning Disabilities, 22, 581-587.

Carter, S. B., & Bassett, N. (1985). Parent to parent goes national. Children Today, 14(2), 30-31.

Chandler, L. K,. & Lubeck, R. C. (1985). Assessing family needs: The first step in providing family-focused intervention. Washington DC: Handicapped Children's Early Education Program. (ERIC Document Reproduction Service No. ED 291 220)

Davis, P. B. (1990). Changing expectations for fathers. Coalition Quarterly, 5 (2), 10-13.

Deardorff, C. A. (1992). Use of the double ABCX model of family adaptation in the early intervention process. Infants and Young Children, 4(3), 75-83.

Deiner, P. L., & Whitehead, L. C. (1988). Levels of respite care as a family support system. Topics in Early Childhood Education, 8(1), 51-61.

DeLossis, R. D. (1985). Infant development program: Special care for special families. Children Today , 14(1), 18-24.

Dunst, C. J., Johanson, C., Trivette, C. M., & Hamby, D. (1991). Family oriented early intervention policies and practices: Family-centered or not? Exceptional Children, 58, 115-125.

Dybwad, R. F. (1990). Perspectives on a parent movement. Washington, DC: Brookline.

Fotheringhan, J. B., & Creal, D. (1974). Handicapped children and handicapped families. International Review of Education, 20, 355-373.

Friesen, B. J., Griesbach, J. H., Jacobs, J. H., Katz-Leavy, J., & Olson, D. (1988). Improving services for families, Children Today, 16(4), 18-22.

Grieffel, G. (1991). Walking on a tightrope: Parents shouldn't have to walk it alone. Young Children, 46(3), 40-42.

Halpren, P. L. (1985). Respite care and family functioning in families with retarded children. Health and Social Work, 10, 138-151.

Hecht, A. (1986, April). Support groups: When going it alone is going nowhere. FDA Consumer, pp. 29-31.

Heighway, S. M., Webster, S. K., & Snodgrass, P. (1988). Supporting parents with mental retardation. Children Today, 17(6), 24-27.

Herman, S. E., & Hazel, K. L. (1991). Evaluation of family support services: Changes in availability and accessibility. Mental Retardation, 29, 351-357.

Hetherington, E. M. (1984). Stress and coping in children and families. In New directions for child development (pp. 20-34). San Francisco: Jossey-Bass, Inc.

Horel, L. (1987). Developing partnerships between families and service providers in rural Vermont. Children Today, 16(1), 17-19.

Hulnick, M. R., & Hulnick, H. R. (1989). Life's challenges: Curse or opportunity? Counseling families of persons with disabilities. Journal of Counseling and Development, 68, 166-170.

Kinney, J., Dittmar, K., & Firth, W. (1990). Keeping families together. Children Today, 19(6), 14-19.

Kobliner, B. (1991, April). When your child is born ill. Money, pp. 112-123.

Koch, R., & Dobson, J. C. (1971). The mentally retarded child and his family. New York: Brunner/Mazel Publishers.

LaBarrera, J. D., & Masterson, D. (1988). Support group helps troubled fathers learn parenting skills. Children Today, 17(2), 10-13.

Lazzari, A. M., & Kilgo, J. L. (1989). Practical methods for supporting parents in early transitions. Teaching Exceptional Children, 22(1), 40-43.

Leviton, A., Mueller, M., & Kaufman, C. (1992). The family centered consultation model: Practical applications for professionals. Infants and Young Children, 4(3), 1-8.

Lillie, D. L. (1972). Parent programs in child development center. First chance for children. Chapel Hill: North Carolina University Technical Assistance Development System. (ERIC Document Reproduction Service No. ED 067798)

Mackeith, R. (1973). The feelings and behavior of parents of handicapped children. Developmental Medicine and Child Neurology, 15, 524-527.

Mash, E. J. (1984). Families with problem children. In New directions for child development (pp. 65-82). San Francisco: Jossey-Bass, Inc.

Perske, R. (1981). Hope for the families: New directions for parents of persons with retardation or other disabilities. Nashville: Abingdon Press.

Perske, R. (1973). New directions for parents of persons who are retarded. Nashville: Abingdon.

Pond, E. F., & Gilbert, C. M. (1987). A support group offers help for parents of hyperactive children. Children Today, 16(6), 23-27.

Powell, T. H., & Ogle, P. A. (1985). Brothers and sisters-A special part of exceptional families. Baltimore: Paul H. Brookes Publishing.

Roberts, R. N., McLaughlin, G. B., & Mulvey, L. (1991). Family support in the home. Lessons from pioneer programs. Children Today, 20(1), 14-17.

Samuels, J., & Balter, L. (1987). How useful are telephone consultation services for parents? Children Today, 16(3), 27-30.

Sandler, A., Coren, A., & Thurman, K. K. (1983). A training program for parents of handicapped preschool children: Effects upon mother, father, and child. Exceptional Children, 49, 355-358.

Sexton, D., Burrell, B., & Thompson, B. (1990). Measurement integrity of the family needs survey. New Orleans: Paper presented at the Mid-South Educational Research Association. (ERIC Document Reproduction Service No. ED 326 547)

Simeonsson, R. J., Bailey, D. B., Huntington, G. S., & Brandon, L. (1991). Scaling and attainment of goals in family-focused early intervention. Community Mental Health Journal, 27, 77-83.

Sloman, L., & Konstantareas, M. M. (1990). Why families of children with biological deficits require a systems approach. Family Process, 29, 417-427.

Sparling, J., Berger, R. G., & Biller, M. E. (1992). Fathers: Myth, reality, and public law 99-457. Infants and Young Children, 4(3), 9-19.

Springer, K., & Kantrowitz, B. (1990, October). The long goodbye. Newsweek, pp. 77-80.

Summers, M., Bridge, J., & Summers, C. R. (1991). Sibling support groups. Teaching Exceptional Children, 23(4), 20-25.

Toseland, R. W., Rossiter, C. M., Peak, T., & Smith, G. C. (1990). Comparative effectiveness of individual and group interventions to support family caregiver. Social Work, 35, 209-216.

Tracy, E. M. (1990). Identifying social support resources of at-risk families. Social Work, 35, 252-256.

Turnbull, H. R., & Turnbull, A. P. (1985). Parents speak out. Columbus: Charles E. Merrill Publishing.

Waggoner, K., & Wilgosh, L. (1990). Concerns of families of children with learning disabilities. Journal of Learning Disabilities, 23(2), 97-113.

Williams, V. (1987). Helping parents of developmentally handicapped children. Techniques, 3, 134-138.

Zeitlin, S., & Williamson. G. G. (1988). Developing family resources for adaptive coping. Journal of the Division for Early Childhood, 12, 137-146.

APPENDIX A

PARENT SURVEY

Parent Survey

Your response to the following statements will assist The First Step Early Intervention Program in better understanding your needs as parents. Results of this survey will help the center in planning programs and materials to assist you. It is not necessary to sign your name. A separate survey form should be completed by each parent.

Please read each statement. Circle the number which best describes your feelings at this time according to the key below.

1= Definitely not a concern/interest
2= Rarely a concern/interest
3= Occasionally a concern/interest
4= Often a concern/interest
5= Definitely a concern/interest

1. I need more information about my child's condition, behavior, or disability. 1 2 3 4 5
2. I would like to meet and talk to other parents going through similar experiences. 1 2 3 4 5
3. I am comfortable bringing my child to the classroom or having the teacher come to my home. 1 2 3 4 5
4. I want to work with my child at home but do not know how. 1 2 3 4 5
5. My partner denies many of our child's problems. 1 2 3 4 5
6. I can discipline my child. 1 2 3 4 5
7. I need to have more time for myself. 1 2 3 4 5
8. If quality respite care were available for my child I would use it. 1 2 3 4 5

9. I need help in explaining my child's problems to friends and relatives. 1 2 3 4 5

10. I would like more time to talk with the staff at the center about my child's needs. 1 2 3 4 5

11. I wish I had someone I could call when I am feeling blue who would just listen. 1 2 3 4 5

12. I need help finding day care for my child. 1 2 3 4 5

13. I need help transporting my child to programs and services. 1 2 3 4 5

14. I need more general information on how children grow and develop. 1 2 3 4 5

15. I need help in paying for things by child needs. 1 2 3 4 5

16. I need help in paying for food and housing. 1 2 3 4 5

17. My partner and I need to meet other couples with similar interests and concerns. 1 2 3 4 5

18. I would participate in an exercise program to relieve stress if one were offered at the center (with child care provided). 1 2 3 4 5

19. I need more information about services in the community for my child. 1 2 3 4 5

20. I am concerned about spending more time with my other children. 1 2 3 4 5

Of the twenty items listed, choose three (3) about which you have the greatest concern. List the numbers below in any order.

____ ____ ____

APPENDIX B

PARENT LETTER

FIRST STEP

Early Intervention Children's Program

1694 Cedar St. **Rockledge, FL. 32955**
3395 Dairy Rd. **Titusville, FL. 32794**

June 18, 1992

Dear Parent/Caregiver,

HOW MAY WE HELP YOU?

The FIRST STEP EARLY INTERVENTION CHILDREN'S PROGRAM feels a strong commitment to working with families as well as children. As we explore this possibility for service to families, we feel it is very important to hear from you regarding your needs and wishes.

Some of you have had an opportunity to complete the attached survey during a visit to the center. For those who have not, a self-addressed, stamped envelope is included for your convenience.

We would like to have a form completed by each parent/caregiver. It is not necessary to sign your name.

We look forward to working together to meet your needs.

With warm regards,

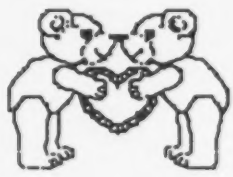
Ernestine Cormany

Ernestine Cormany, Children & Youth Services Manager

EC/mw

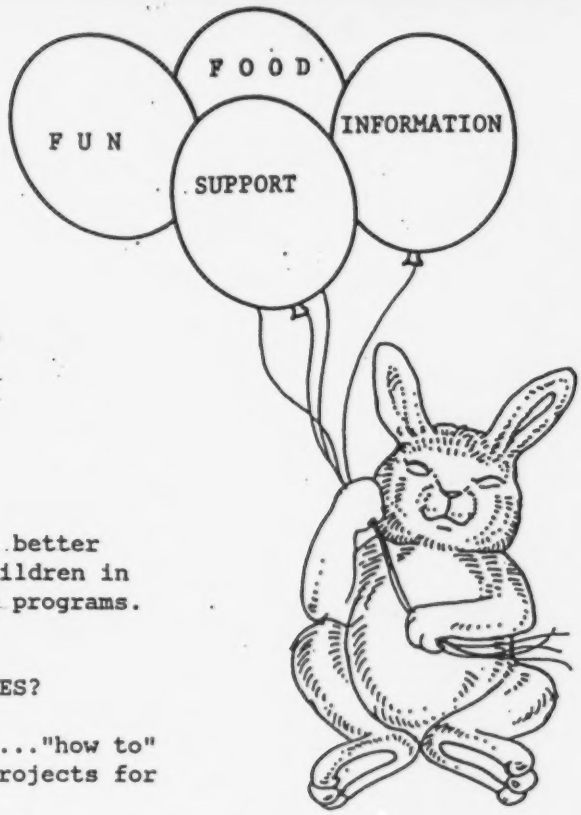
Attachment

arc BREVARD INC.
ASSOCIATION FOR RETARDED CITIZENS



APPENDIX C

PARENT SUPPORT GROUP INFORMATION SHEET



FIRST STEP PARENT GROUP

ARC-BREVARD, INC.

WHAT IS IT?

A group which meets monthly to get better acquainted with others who have children in the center based and/or home-based programs.

WHAT HAPPENS AT THE MEETINGS/ACTIVITIES?

A good time...information exchange..."how to" activities to use at home...work projects for the classrooms...dinners and cookouts...sharing of concerns...tips on advocating for services...casual conversation...and more.

WHO MAY ATTEND?

Any parent, foster parent, grandparent or guardian who has a child (birth to age three) enrolled in the First Step program. Parents whose children are recent graduates are also welcome to continue with the group.

HOW CAN I GET INVOLVED?

Meeting/activity notices go out in advance. Everyone is welcome...bring a friend if you like! Let us know if you need transportation (we may be able to pick you up in the agency van)...stay as long as you can (most meetings last a couple of hours)...child care can be provided for your enrolled child and other "little ones" (let us know by calling 690-3464).

HOPE TO SEE YOU OFTEN!

APPENDIX D

MEETING/ACTIVITY NOTICES

YOU'RE INVITED

TO: ITALIAN DINNER NIGHT

FOR: FAMILIES OF EARLY INTERVENTION CHILDREN

WHAT: AN EVENING OF FUN AND FELLOWSHIP...an opportunity to get acquainted..casual dress..child care provided..prizes for lucky winners!

WHEN: WEDNESDAY, JUNE 10, 1992 - 6:30 P.M.

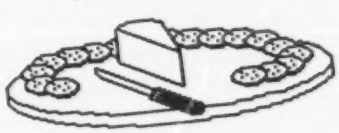
WHERE: FIRST STEP EARLY INTERVENTION CHILDREN'S PROGRAM
ARC CENTRAL LOCATION
1694 CEDAR STREET, ROCKLEDGE

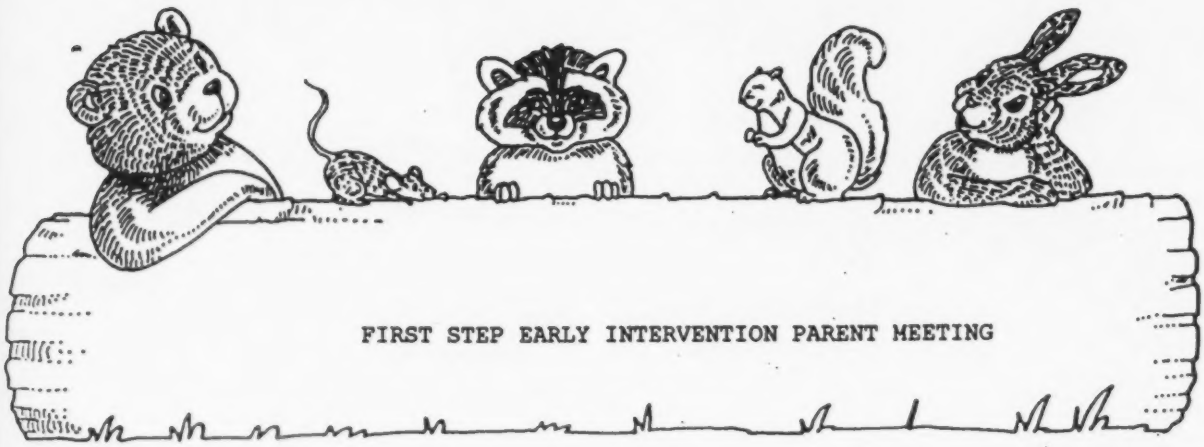
COST: "AN ITALIAN COVERED DISH" (If you don't have time to prepare--pick up a pizza to share!)

(The center is making plans to furnish salad, bread, drinks and dessert)

P.S. Please call Joanne to let us know how many children to plan for in child care (636-1463).

P.S.S. We are excited about our "first ever" get together to include all center based and home based families. See you there!





FIRST STEP EARLY INTERVENTION PARENT MEETING

WHEN: Tuesday, July 14, 1992
at 9:00 a.m.

WHERE: FIRST STEP EARLY INTERVENTION
1694 Cedar St., Rockledge, Florida
Phone: 636-1463

PROGRAM: "Future Directions" - Where Do We Go From Here?

BONUS: Informal Networking Time

PLEASE PLAN TO ATTEND AND BRING A FRIEND!

*CALL IF YOU WILL NEED A SITTER FOR SIBLINGS.

BACK TO SCHOOL

"PARENT DAY"

WHAT: Join other parents and staff in a "work project" (making art easels for the classrooms), a slide show of your "kids", and a cookout!

WHEN: Saturday, August 29, 1992

TIME: 3:00 p.m. Work Project Begins
5:00 p.m. Cookout

WHERE: First Step Early intervention Children's Center
1694 Cedar St., Rockledge, Florida

PLEASE BRING: A covered dish to share and the meat you wish to grill (hot dogs, hamburgers, etc.). The center will provide grills, drinks, ice, and paper products.

NOTE: Children are also invited. "Moms" are asked to volunteer for 1/2 hour babysitting shifts from 3:00 - 5:00 p.m. while dads are participating in the work projects. The center will provide a sitter during the cookout and slide show. Please call Joanne (636-1463) to indicate your plans.

APPENDIX E

RELEASE OF INFORMATION FORM

FIRST STEP

Early Intervention Children's Program

1694 Cedar St. Rockledge, FL.32955

Dear Parent/Guardian,

As a means of including you in our parent support network, it is necessary for us to obtain your permission to share your name, address, and phone number with the officers of the parent group.

This information will not be published and will be used only as a means of contacting you with pertinent information regarding the parent group or early intervention activities for your child.

Please complete the form below, sign it, and ask a friend, neighbor, or other family member to witness it. Return the entire sheet to the First Step Early Intervention office.

I hereby authorize the First Step Parents Support Group to release my:

Name:_____

Address:_____

Phone Number:_____

to the officers of this group.

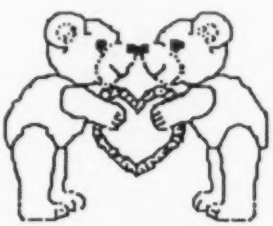
Child's Name:_____

Parent/Guardian's Signature:_____

Date:_____

Witnessed by:_____

Date:_____



APPENDIX F

INDIVIDUALIZED FAMILY SERVICE PLAN MODEL

FAMILY SUPPORT PLAN *(Page 1 of 5)*

Date *(mm/dd/yy)* ☐☐-☐☐-☐☐

Name _____
(last) (first) (MI)

ID # _____

Date of Birth *(mm/dd/yy)* ☐☐-☐☐-☐☐

Age _____ (under 2 years of age, define age in months.)

Background Information

Other names: _____

Nickname: _____

Referral date: _____

Family Support Plan Meeting Date: _____

Review dates: _____

_____

_____

Family Members

Names (and ages of children)	Relationship in family

FAMILY SUPPORT PLAN TEAM

Role	Name/Program/Address	Phone #('s)	Copy
Parent			
Primary Service			
Coordinator			
Medical Care			
Provider			

FAMILY SUPPORT PLAN *(Page 2 of 5)*

Date *(mm/dd/yy)* | | | - | | | - | | |

Name _____
(last) (first) (MI)

ID # _____

Date of Birth *(mm/dd/yy)* | | | - | | | - | | |

Age _____ (under 2 years of age, define age in months.)

Reason for referral for services:

What are your, or your child's, strengths and personality traits which will help gain new skills?

What are your concerns, priorities and resources for your child and/or family?

Summary of Health and Medical Status

Include Vision, Hearing and Immunizations

FAMILY SUPPORT PLAN *(Page 3 of 5)*

Date *(mm/dd/yy)* ☐☐-☐☐-☐☐

Name _____
(last) (first) (MI)

ID # _____

Date of Birth *(mm/dd/yy)* ☐☐-☐☐-☐☐

Age _____ (under 2 years of age, define age in months.)

Summary of Assessment/Evaluation:
(include Cognitive, Communication, Physical (gross & fine motor), Social or Emotional and Adaptive Skills)

Developmental Area	Summary of Present Status (include date of assessment/evaluation)

Developmental Area	Concern Related to Each Developmental Area

Eligiblity results:

FAMILY SUPPORT PLAN *(Page 4 of 5)*

Date *(mm/dd/yy)* ☐☐-☐☐-☐☐

Name _____
(last) (first) (MI)

ID # _____

Date of Birth *(mm/dd/yy)* ☐☐-☐☐-☐☐

Age _____ (under 2 years of age, define age in months.)

ACTIVITY PLAN

Outcome What do you want for yourself? For your child? For your family?
*(*Annual goals/short term objectives)*

Date:

Action/Resources	Description of Resources/Services	Evaluation
What needs to happen to reach this outcome? Who's responsible? *(Agency, Funding source)*	In what ways will this happen? *(Method, frequency, intensity, duration, and location)*	Are these outcomes reached? What needs to happen next? *(Criteria)*
		Date:

*Only if required by funding agency

FAMILY SUPPORT PLAN *(Page 5 of 5)*

Name _____
(last) (first) (MI)

ID # _____

Date of Birth *(mm/dd/yy)* ☐☐-☐☐-☐☐

Age _____ (under 2 years of age, define age in months.)

PARENTAL CONSENT: I have participated in the development of this plan and agree to the provisions. I have been informed of due process rights.

DATE	PARENT/GUARDIAN SIGNATURE

FAMILY SUPPORT PLAN MEETING ATTENDEES

MEETING DATE	SIGNATURE	AGENCY	PHONE #